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ABSTRACT

Families of nursing home residents often perceive the care provided by the nursing home staff to be inadequate or inappropriate. Consequently, conflicts and misunderstandings frequently arise between staff and family members. A study was conducted in two midwestern nursing homes which investigated the perceptions of family and staff about the care provided to nursing home residents. The study used a grounded dimensional analysis (grounded theory) involving extensive interviews with 60 family members and 25 nurses at two facilities. Results indicated that family members often perceived themselves as ultimately responsible for making decisions about care and evaluating the effectiveness and appropriateness of care. In contrast, professional staff perceived themselves as ultimately responsible. These differences in attribution of responsibility were found to be based on the incompatability of definitions of expertise. Families perceived expertise in caring for the elderly to be based on personal, biographical experience with a particular resident. More general theories of aging were seen by families as having very little credibility. Staff generally perceived expertise as being based on more formal knowledge gained from a general knowledge of aging and disease process. These differences in source of expertise and responsibility attribution were reflected in what staff labeled family interference with care and what families labeled poor care. A three-page bibliography concludes the document. (NB)

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Family Involvement in Nursing Home Care

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Family caregiving of older relatives is an extensively researched area. Most of this research on family caregiving has looked at elderly who are living in the community either alone or with family rather than at those in institutional settings. In fact, institutionalization has generally been viewed as the termination of family caregiving, as a transfer from family to institutional care. Families have also been relatively absent in research on relocation of frail elderly to long term care settings apparently based on the assumption that significant family caregiving ceases after institutional placement.

Since the mid 1970s there has been a small number of studies focusing on family involvement with elderly relatives who have been placed in long term care institutions, (integration into the community or family). These studies have consistently documented a continuation of family relationships after institutional placement. Those that were close prior to institutional placement are likely to continue to be close while those that are strained and conflictual are also likely to continue to be so. Based on these studies, nursing home placement appears to neither represent nor cause abandonment by families.

The nature of family involvement with nursing home residents has been the focus of only a few studies.

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A few studies have suggested that families provide non technical care while the staff provide technical care, and that over-involvement of family in technical care is likely to be perceived by staff as interference. At the same time over involvement of staff in non technical care could discourage family involvement. Leading to conclusions that a balanced and coordinated effort which involves clear distinctions in the care provided by each group will result in optimal care.

More recently (late 70s early 80s) studies have been reported which looked at family versus staff attribution of responsibility for the elderly resident's care (Chenitz, 1984; Fauerbach, 1984; Smith & Bengtson, 83; Shuttlesworth et al., 1978). These studies attempted to distinguish 'family members' perceptions of responsibility for caring tasks. Respondents were asked whether family or staff was primarily responsible for a given task or whether both groups were jointly responsible. A consistent trend was discovered. In each of these studies families attributed more overall responsibility to themselves for their relative's care than staff attributed to families. There were very few tasks that family and staff agreed were clearly the responsibility of the family (usually 3-4 out of 50-100). In each of these studies the magnitude of disagreement was modest and task attributions within family groups were not consistent.

The study reported here today focused on family perceptions of the care provided by themselves and the nursing home staff. The purpose of the study was to build on the previous research on family involvement in nursing home care as well as a study I recently completed on family caregiving at home. Let me briefly sketch the findings of that earlier study. Family caregivers perceived their most important to be protective caregiving, that is, any

activity carried out for the purpose of protecting the parent's self-image and the parent/child relationship. Caregivers consistently perceived this to be more important than instrumental care, bathing, feeding, toileting, transporting, etc. They expended significant amounts of time and energy in preventing the elderly parent from discovering that any caregiving was occurring. In particular, caregivers were careful not to let their elder parents discover that a role reversal had occurred, which might threaten the parent/child relationship. These efforts explained much of what might otherwise have been labeled as the parent's denial of being care for.

A central question for the study I will describe was whether and how these caregiving categories were useful in explaining family involvement in nursing home care.

Method

The method used for the study was a grounded dimensional analysis which is a combination of grounded theory and dimensional analysis. Subjects were recruited by contacting family members identified in the medical records of eighty-five nursing home residents. Everyone who agreed to participate was interviewed. They lasted 30-90 minutes each, were taped and transcribed to facilitate a line-by-line dimensional analysis (systematic coding process for grounded qualitative data).

Questions were very general and undirected. Subjects were simply asked to talk about what it was like for them to have a relative in a nursing home, and about the care provided by themselves and the staff.

Findings

Consistent with the findings of past research, families perceived a general disagreement over attribution of responsibility between themselves and

the staff. What is different about this study is that families perceived a much greater disagreement between themselves and the staff than was indicated in past studies, and that distinctions were not primarily based on responsibility for task performance. Family members attributed responsibility for the performance of most tasks to the nursing home staff. However, they attributed responsibility to themselves for monitoring and evaluating the effectiveness and quality of these tasks, (technical or nontechnical). Rather than a transfer of responsibility from family to staff, this is conceptually equivalent to a family hiring technical expertise but maintaining a supervisory and evaluative and educational role.

The work that families described doing in nursing homes to assure the quality of care their relative receives from staff and includes: monitoring and evaluating the quality of care provided by the staff, teaching the staff how to deliver high quality care, picking up where the staff has failed, (undoing damage, filling gaps) as well as directly providing protective care to their relative.

Family members claim the ability and the responsibility of assessing the quality of care provided by the staff based on how they conceptualize expertise. Embedded in interview data is a clear distinction between technical and biographical expertise. Technical expertise includes knowledge and skills related to disease process and treatments and is gained from a general knowledge of aging and disease process. Biographical expertise is an intimate knowledge of the elder relative and can only be gained from a long, shared family history with the older person. Specifically, biographical expertise gives the caregiver privileged insight into the older person's likes, dislikes, idiosyncracies, needs and vulnerabilities. The significance

of this distinction lies in the families' belief that good quality care requires both types of knowledge and that biographical expertise is required to carry out protective caregiving . Since the staff has direct access to biographical information it must be provided by the families. Clinical care must be done in a way that takes account of the older individual's personal biography (likes, dislikes, needs and vulnerabilities). This creates a partnership between the family and staff and is a much more enmeshed caregiving relationship than a division of tasks between the two groups. It also mandates family involvement in technical tasks performed by the staff.

Family members see themselves as primarily responsible for monitoring the care to be sure it combines protective caregiving and technical expertise. For example, family members were most upset when their elder relative was given a message that their care was difficult for staff, that they were a burden or that the older person's personal preference was silly or unimportant (clothing, room decor, bedtime, etc.).

Because families are not present 24° a day and do not observe much of the care that is given to their relative they develop ways to gain information about the quality of care given in their absence. They described three methods for acquiring evidence about the quality of care. The most frequently cited was assessing the outcome. If the older relative was found to be depressed, hopeless, uncomfortable, withdrawn or agitated, family members consistently interpreted this as evidence of poor care, regardless of its technical quality. The quality of unobserved care is inferred from these outcomes. Good quality care would have prevented such an outcome. Conversely, a cheerful energetic emotionally engaged relative was evidence of high quality care. Outcome was consistently perceived as the crucial index.

Family members also subtly observed the care provided to residents whose families were absent as evidence about the care provided when the staff was not being observed by the residents' family. Most family members agreed that the more time family spent in the facility, the better the care provided by the staff, (Supported by study). Third, family members asked their elderly relatives how the care was during times when the family was gone. This study was problematic because the types of illness which many of these elderly residents suffer from interferes with the residents ability to process events (dementias, confusion, depression).

Protective caregiving in the nursing home was for the purpose of maintaining hope (generally for recovery), maintaining family connectedness, maintaining control of their environment and themselves and maintaining dignity.

Maintaining family connectedness was primarily related to family visiting, day trips for residents. and memorabilia in the room. The other three were much more likely to involve collaborative protective caregiving between family and staff. Maintaining hope of recovery even under the most disconfirming circumstances was of great importance to many families, whereas they perceived staff to be continually undermining this work by confronting residents with the reality of the situation. Two specific areas of conflict were noted frequently. First, family members expressed a great deal of inner conflict over staff efforts to encourage a resident's independence such as forcing the resident to engage in self care activities that had become difficult (feeding themselves). Staff defined this as rehabilitational while families were more likely to see this cruel or neglectful. Families often tried to protect the parent from full knowledge of his or her deficits. While

staff felt openness with residents was an essential component to the rehabilitation model. Staff, on the other hand, described the families' response as undermining a rehabilitation program and encouraging independent behavior. In contrast to their feelings about independence with routine activities families saw the formal rehab program (P.T.) as crucial to maintaining the resident's hopes. A cutback of termination in the formal rehab program was interpreted as a signal that the staff had given up on the resident, had lost hope in any chance for recovery. While problems of staffing and reimbursement were more likely causes, families felt betrayed by any dilution in these programs. (Over 80% Physician expectation after intro skilled-rehab).

Maintaining the elderly resident's dignity was a central and difficult goal for family members and also required biographical expertise. This was based on a respect for personal preferences, needs and vulnerabilities. Families most frequently cited assaults on personal dignity related to messy personal appearance, exposure of intimate information to outsiders, loss of control of body functions, feelings of being a burden to the staff and family (study). Families perceived frequent conflict with staff over each of these areas, again related to the balance between encouraging independence and protective care.

Finally, families described problems relating to the resident's control of self and environment. Maintaining the ability to decide what they would do, and when they would do it were perceived by family members as crucial - when to get up, go to bed, move from one chair to another, visit with friends, etc. Conflict occurred frequently when the resident's preference was

inconsistent with staff schedule or medical order (not to take pills now, skipping a treatment what time to have her hair done or go to P.T.).

A major problem perceived by families was the staff's control of timing and pacing of activities. The staff, on the other hand, frequently complained to families allowing the residents this sort of control resulted in spoiling, creating unrealistic expectations that the staff could not carry out in the family's absence.

Family members engaged in three general strategies (or combinations) to insure high quality care (combined protective and technical): 1) Increased the amount of time families spent in the facility; 2) Monitor and teach the staff how to do it better (problems); 3) give up.

In summary, the centrality of protective caregiving in combination with the inability of family members to be present all the time, creates the need for a collaborative partnership rather than a division of labor between staff and families. We are currently looking at data from staff of same facility which should yield further insights into the process of collaboration.

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